Ashmore, Richard D., and Jussim, Lee, eds. *Self and Identity: Fundamental Issues*. New York, NY: Oxford University Press, 1997, 256 pages, $28.00 softcover.

Reviewed by Linda R. Mona, Ph.D., Research Associate, World Institute on Disability, Oakland, CA.

In the late 1800s, the study of the self surfaced within the field of psychology with William James' book 'The Principles of Psychology,' released in 1890. Since that time, various theorists, including individuals studying the disability experience, have studied aspects of the self and identity and have proposed a wide array of theories addressing these constructs. *Self and Identity: Fundamental Issues* presents the historical progression of the exploration of self and identity-related constructs in addition to providing a critical analysis of these perspectives. Given that the editors of this book did not impose specific meanings on the terms 'self' and 'identity,' the reader is able to read each chapter as a separate and unique approach to this topic area.

This book is the initial volume of a three-part series based on a Rutgers University symposium on self and social identity held in 1995. Chapters within this book are organized around two themes: contrasting perspectives on the nature of self and identity, and contexts that are critical for understanding self and identity. In addition, the chapters address two contrasts: self as multiplicity versus unity of identity, and personal versus social nature of self and identity. Three critical contexts are also examined: history, culture, and modern American society at the end of the Twentieth Century. Within these proposed parameters, the chapters are well organized and easy to grasp. Even those fairly unfamiliar with psychological theory can quickly begin to understand the authors' intended direction and theoretical analyses.

The reader may initially question the degree to which this book facilitates our understanding of Disability Studies. The answer to this question is really quite readily available. Investigating broad-based theories of self and identity helps create a more comprehensive understanding of disability identity, disability culture, and the ways in which social and cultural factors can influence how people with disabilities view themselves. This information is valuable because it helps to create an interdisciplinary link between Disability Studies and psychology in further developing a knowledge base about the disability community. This is a valuable partnership in that it has the potential to help respective disciplines understand each other more fully and, in turn, to utilize common theoretical underpinnings when explaining the breadth of the human experience.

Overall, this piece is a great foundation for individuals of all disciplines who are interested in topics associated with the self. Scholars of Disability Studies may find this book helpful when examining issues of disability identity and/or the effects of social factors that influence how people with disabilities perceive themselves. Although not specifically designed to address disability issues, the acknowledgment of the social experience of life makes this text applicable to the disability experience. In summary, this book is recommended as a springboard in beginning to study issues of the self and identity within the realm of Disability Studies as well as within other academic fields interested in this area.

Bannerji, Himani. *Thinking Through: Essays on Feminism, Marxism and Anti-Racism*. Toronto, CA: Women's Press (Suite 233, 517 College Street, Toronto, Ontario, Canada M6G 4A2), 1995, 198 pages, $14.95 softcover.

Reviewed by Kate Kaul, Social and Political Thought Programme, York University.

In *Thinking Through*, Himani Bannerji is consistently engaged with the work of Franz Fanon, Karl Marx, and Dorothy E. Smith, but these are only a few of the many writers with whom she is thinking in these seven short essays, which range from the theoretical to the poetic. (One essay is reprinted from Bannerji et al.'s *Unsettling Relations: The University as a Site of Feminist Struggles* [Women's Press, 1991]). The collection works beautifully; in the essay 'In the Matter of X: Building Race into Sexual Harassment,' Bannerji offers a direct application of the theoretical work of her first

few essays. In 'The Sound Barrier: Translating Ourselves in Language and Experience,' Bannerji continues her exploration of language, identity, and experience, working theory into poetry in 'a form that is both fragmentary and coherent . . . both creative and critical' (p. 179).

What are the implications of this book for Disability Studies? The essays directly address feminism, Marxism, and anti-racism, rather than disability, but Bannerji's notion of 'thinking through' is more than a nice turn of phrase; it not only calls for the integration of gender, race, and class in analysis, but it also suggests the implication of any identity project in concrete social and historical relations. *Thinking Through's* discussions of identity politics and named agency, inclusion, and the politics of difference, and the relation of experience to knowledge, are immediately relevant to the debates and concerns of contemporary Disability Studies.

Following Marx, Bannerji argues that a historical materialist understanding of experience, which treats it as an interpretive relation rather than valorizing any person's or group's experience as a repository of 'truth,' provides a possible active knowledge apparatus, 'the kind of knowledge which can produce social change' (pp. 87-88). Bannerji's critique of the 'common-sense' racism, which, she argues, organizes feminist discourse, also has interesting implications for Disability Studies, both as a field that investigates related, organizing differences and as a discourse that, like feminist writing, works within a social and historical context.

Bowers, Tressa. Alandra's Lilacs: The Story of a Mother and Her Deaf Daughter. Washington, DC: Gallaudet University Press, 1999, 158 pages, $13.95 softcover.

Reviewed by Alexa Schriempf, Philosophy, University of Oregon.

A memoir of mothering a deaf daughter, this book is a recounting of how a hearing mother learned to accept her daughter as Deaf. Tressa Bowers suspected her daughter, Alandra, to be deaf at five months. She was chastised by her pediatrician's admonition that she be reasonable in appraising her daughter: 'Because you lost the first baby, perhaps you are looking for something to be wrong with this one' (p. 12). This was only the first of many comments that marked Bowers' struggles to provide the best she could for her daughter.

Near the age of two, Alandra was finally diagnosed as deaf. The doctor who made the diagnosis provided no recommendations and little advice, warning Bowers that her daughter would not be able to speak and, subsequently, could not be educated. Fortunately for Alandra, Bowers knew a mother of a deaf child who pointed her towards assistance. However, as this was rural America in 1968, Bowers found herself amidst a strong oralist presumption that all deaf children can be 'cured' and made as close to 'hearing' as possible. Even when presented with an opportunity to introduce Alandra to a deaf environment in a residential school, she still believed in the oralist tradition.

Economic needs necessitated several moves during Alandra's childhood. In the process, the two experienced several learning environments, ranging from pure oralism, Total Communication (a combination of sign and spoken language, or the 'anything goes' method, to get the message and ideas across), a residential deaf school using Signed Exact English, and mainstream public schools using interpreters. The constant educational change combined with domestic upheavals made Alandra's education difficult to manage -and, yet, Alandra went to college. Ironically, the greatest challenge of all was for Alandra to be totally accepted by her family. Rejected by her maternal great-grandmother at age two, and approached awkwardly by most other relatives, it took the power of sign language to have the family accept Alandra on her own terms. The tragedy is that Bowers did not appreciate the beauty and the rightness of ASL for Alandra, and it is this slow recognition that seems to grieve Bowers throughout this memoir. Bowers' final analysis is rather biased against oralism; her support for total communication is shortsighted. A more complete and fair assessment of deaf children's education should recognize that need and ability as well as the degree of hearing impairment play paramount roles in choosing communication systems for deaf children.

I recommend this book mostly for new hearing parents of deaf children; they would appreciate a personal account of the consequences of one hearing parent's decision and situation. It should be emphasized, however, that this book is a personal journey and is not a study of how to evaluate

educational philosophies, materials, methods, and needs based on individual differences in the hearing-disabled community.

Brentari, Diane. *A Prosodic Model of Sign Language Phonology.* Cambridge, MA: The MIT Press, 1998, 396 pages, $45.00 hardcover.

Reviewed by Lois Bragg, Gallaudet University.

Diane Brentari, a hearing linguist at Purdue University, is one of perhaps a half dozen scholars in the world who specialize in the phonology of a signed language. The discipline may seem, at first blush, oxymoronic - the study of signed language articulation was originally called cheirology - but, in its study of the formally limited set of handshapes, movements, and places of articulation that are used to construct signs in various natural signed languages, it reveals a system fully parallel to audist phonology and of great interest and value to phonologists of spoken languages. *A Prosodic Model* is addressed to just such a readership and, thus, is largely beyond the scope of this review. In keeping with *DSQ* book review policies, I evaluate instead the implications Brentari's work may have for the field of Disability Studies.

These implications are bleak. First, Brentari's choice to write for the colleagues in spoken language linguistics among whom she must build her reputation is certainly understandable, but it means that the book is largely inaccessible to Deaf readers, even Ph.D.s in linguistics. Brentari has, thus, like any Nineteenth-Century Orientalist, come among us, learned our language, and gone back home to write us up in a venue to which we have no access - in other words, this is an 'about us without us' book.

Second, Brentari's example signs and sentences are all too often unidiomatic or incorrect. For instance, in illustrating subject/verb/object agreement, she constructs a sample sentence in ASL and translates it as 'I asked John, 'Where are you going?' (p. 18). Her ASL sentence, however, is nonsense because it mistakenly uses the ASL verb 'request' rather than the correct 'query,' an error sometimes found among beginners and caused by the pernicious habit of English glossing. It would be interesting to speculate why MIT did not consult with Deaf scholars to insure that Brentari's examples were good ASL: It seems that the mainstream presses still cannot grasp that Deaf people are the experts in their own language and culture.

Cross, Merry. *Proud Child, Safer Child: A Handbook for Parents and Carers of Disabled Children.* London, England: The Women's Press Ltd. (Distributed by Trafalgar Square, North Pomfret, VT 05053), 1999, 216 pages, $15.95 softcover.

Reviewed by Nancy Vitalone-Raccaro, Ph.D., Assistant Professor, New York Medical College, with Heidi Bammert, Peer Support Staff, Consumer Resource Center at Westchester Institute for Human Development.

Proud Child, Safer Child is a unique book that examines the issue of protecting children with disabilities from abuse. The author's stated objective is to help readers by suggesting ideas about how to build a child's self-esteem and about how to promote the safest practices among those entrusted with caring for children with disabilities, parents included.

Merry Cross has indeed succeeded in her goal to help readers feel better equipped to protect the children for whom they care. The book is replete with food for thought for even the most conscientious parent or professional. Information is presented in a well-organized, forthright manner. The author's deep commitment to the protection of children with disabilities from abuse is evident in her frank discussion of pertinent issues and her thoughtful presentation of accessible advice.

The book is divided into three sections. The first section, 'Our Children in Our Care,' deals with the immediate issues involved with self-image, communicating with children, intimate care, and sexuality and sexual relationships. Merry Cross appropriately begins her book presenting information about self-esteem. This is an apt beginning because promoting self-esteem in children with disabilities is a central theme that runs through the entire book. The author contends that children with high self-esteem feel empowered to take on the many challenges that come their way, a status that, ultimately, will reduce the risk of abuse and will increase safety. Advice for building a child's self-esteem

is provided early on and revisited often in subsequent chapters.

The second chapter takes an in-depth look at ways of communicating with children with a range of disabilities to help avoid the possibility of abuse and to ensure that children know how to disclose any difficult or unpleasant experiences. The chapter on intimate care is thought-provoking and provides a wealth of useful information. Merry Cross talks openly about protecting children from sexual abuse and other considerations with regard to sexual development.

Section Two, 'Our Children in the Hands of Professionals and Institutions,' covers issues related to dealing with a plethora of professionals, medical interventions, and schools. Parents may find this section particularly useful. Information on the pros and cons of medical intervention is provided. Likewise, suggestions parents can make to guide institutions toward safer policies and procedures are included.

The final section offers clear guidance on how to recognize and assess the signs and indicators of abuse and what to do if abuse is suspected. The strategies for creating the best possible context for recovery from abuse may be helpful to families who have encountered abuse.

One point made in the book needs to be clarified because it may have less applicability in the U.S. than in England, where the author presumably resides. A statement was made that 'There is no system of which I am aware, provided to children using non-verbal communication (other than BSL) that provides such a concept' (pp. 56-57) as assertive language (e.g., 'go away and leave me alone') and basic terms for sexual body parts or abusive acts.

Currently, a number of augmentative communication systems can be programmed or modified to include topics pertinent to the user. Families and professionals are advised to consult with a speech and language therapist appropriately trained in augmentative communication to address this particular issue.

Proud Child, Safer Child is an easy read that is full of helpful information to make parents and carers of children with disabilities aware of the risks of abuse and to equip them with myriad ways to reduce those risks.

Reading this book is time well spent.

Delgado, Gary. *Beyond the Politics of Place: New Directions in Community Organizing* (2nd Ed.). Berkeley, CA: Chardon Press, 1997, 96 pages, $25.00 softcover.

Reviewed by Patricia Sisco, M.Ed., National Chair for the Canadian Association of Independent Living Centres.

Beyond the Politics of Place is a monograph analyzing the wide spectrum of changes that has taken place in the organizing and development of community organizations over the last forty years. Emphasis is placed on the efforts that people of color have made to overcome barriers, but the monograph does touch on other identity-based constituencies with social justice concerns. The changes made in disability organizations fit well into the analysis made in this monograph.

Delgado shows how political and economic changes over the years have influenced the rise and fall of community organizations. The 1960s emphasized the 'elimination of poverty,' and the end of the century is emphasizing 'elimination of entitlements' and 'privatization of poverty.' These changes have forced grassroots organizations to play a more and more important role.

The monograph starts with a historical overview of the various approaches used by community organizers. The purpose of these organizations was to give a voice to the people who could not be heard and, as the author points out, to work as a vehicle for social reform and a mechanism for the expansion of democratic principles (p. 9). The organizations that existed through the 1970s and early 1980s ranged from direct membership organizations to coalitions and institution-based organizations. A description of each approach is clearly laid out in a table (p. 17). The author then describes the crises that many of the organizations were in due to 'political and economic trends, inherent limits of a local, geographically based organizing model, and the relationship of CO [community organizing] to other social movements' (p. 19).

Delgado goes on to describe the types of organizations that survived the crises, those being

organizations that have training components and those that represent people of color. Organizations having training components served to revitalize the community organizations by initiating projects, developing leaders, and developing organizers. The communities of color 'were forced to develop approaches and create organizations that reflected their own sensibilities and the interest of their communities' (p. 29). The author concludes the monograph with an excellent analysis of the accomplishments, limitations, and new developments of the community organizations.

This book, or monograph, is recommended reading for anyone involved in or interested in community organizations. It gives a clear, concise, and detailed description of the history of community organizations in the United States. Not only does it give information on how and why community organizations developed, but it gives guidance to the type of support needed to keep important organizations going in the future.

Ewalt, Patricia L., Freeman, Edith M., Kirk, Stuart A., and Poole, Dennis L., eds. *Multicultural Issues in Social Work.* Washington, DC: NASW Press, 1996, 578 pages, $37.95 softcover.

Reviewed by R.C. Saravanabhavan, Center for Disability and Socioeconomic Policy Studies, School of Education, Howard University.

Multicultural Issues in Social Work is a unique collection of 38 essays covering the multifaceted diversity issues relevant to the field of social work. The book is divided up into six parts, namely: muticultural practice, law and policy, populations, education, health care, and service delivery. Essays, contributed by various authors, are presented as chapters under each part. The major purpose of this collection is to emphasize the ever increasing need for social work professionals to acknowledge, appreciate, and fully understand cultural diversity. As the editors point out in the introduction, this book is an attempt to present multicultural issues in a positive and inclusive perspective. They want to dispel the notion that 'a focus on multiculturalism emphasizes cultural differences in a negative way' (p. xii).

Part I, with the title 'Multicultural Practice,' starts with a chapter contributed by members of five different racial/ethnic groups (African Americans, First Nations, Asian Americans, Latino American, and European Americans). They write about multiculturalism from their professional and individual perspectives. All of these authors stress the need to value the richness and diversity of all groups. Other chapters in this section strike the keynote of this book by explaining: (a) how the demography of the nation has changed from just two racial groups (White and non-White) included in the 1940 U.S. Census to the 43 racial categories and subcategories of the current period; and (b) that social workers have a responsibility to consciously reverse the historic binary system by seeking to understand a client's full background, including the client's perceptions of his/her identity.

Part II, which focuses on law and policy, includes six chapters. These chapters deal with issues that have strong policy implications. For example, Chapter 9 illustrates that one-third of the population in the country who are immigrants are of Asian or Hispanic origin, unlike in the past when most immigrants came from Europe. Part III discusses issues related to selected populations, such as American Indians, Asians, African Americans, and people with hearing impairments. Part IV, with issues such as problems of inner-city school children, older Asians and Pacific Islanders, and culturally relevant programs for American Indian children, underscores the importance of appropriate educational policies and strategies.

Parts V and VI, which focus on health care and service delivery, contain essays with very broad and diverse issues such as HIV, sickle cell anemia, NAFTA's impact on American and Mexican health, and four selected studies on perceptions and utilization of services among African Americans, Hispanics, and Asian Americans.

This book takes diversity issues beyond race and ethnicity. It includes issues pertaining to all age groups (children, youth, adults, and older adults) and to certain disability populations. Despite the 38 chapters, it is still impossible to capture all the issues of multiculturalism. However, the book has succeeded in bringing the essential problems to the forefront. It is not a book on 'face, food, and fiesta' of different racial ethnic groups. Most chapters are thoughtful essays and research findings that

identify the need for a consumer-based and consumer-empowered approach to social work practice.

This book is a valuable resource for social work students and practitioners.

Foster, Patricia, and Swander, Mary, eds. *The Healing Circle: Authors Writing of Recovery.* New York, NY: Penguin Putnam Inc., 1998, 288 pages, $13.95 (U.S.) softcover, $18.99 (Canada) softcover.

Reviewed by Laura Hershey, Freelance Writer, Denver, CO; Founder, Crip Commentary website which can be found at <http://ourworld.compuserve.com/homepages/LauraHershey>.

In the increasingly-popular literary genre of memoir, storytelling is once again becoming culturally significant. Personal narrative allows the writer to expose the most intimate, often painful details of her life. At their best, personal narratives can offer rich discoveries that transcend the merely confessional. The potential of memoir to illuminate the culture of disability and illness has only occasionally been fully realized. Too often, memoirs of disability and illness are either artificially cheerful, or clumsily narrated, or simply self-absorbed. A few, through either literary skill or political commitment, have risen above those pitfalls to be genuinely interesting.

The Healing Circle is a rich, refreshing, literary contribution to the category of personal memoir. This anthology offers a range of engaging essays that explore experiences of recovery from illness and/or injury.

Several of the essays make clear that recovery is not always a simple matter of 'getting better.' Some of the writers, rather than reaching the end of a journey called recovery, instead come to terms with an ongoing dance between illness and wellness. Our society has tended to define illness as a problem, and recovery as the solution. But the reality is sometimes more ambivalent. Lauren Slater in 'Blue Baby' writes about her lifelong struggle with obsessive-compulsive disorder (OCD) and about the medication prescribed as treatment. 'Prozac,' she writes, 'was a grief, because it returned me to the regular world with consequences I never expected' (p. 16). Slater challenges the typical understanding of 'normal,' especially when that characteristic is brought on by pharmaceuticals. 'Such drugs, supposedly, return the patient to a normal state of functioning,' Slater writes. 'But what happens if such a patient, say myself for instance, has rarely if ever experienced a normal state of functioning? What happens if such a patient has spent much of her life in mental hospitals, both pursuing and pursued by one illness after another? . . . If this is the case, then the 'normal state' of functioning that Prozac ushers in is an experience in the surreal . . . a disorientation so deep and sweet you spin. A soaring high. For this very reason, Prozac, make no mistake about it, blissed me out and freaked me out and later on, when the full force of health hit me, sometimes stunned me with grief' (p. 17).

For other authors, recovery is a linear and forward-moving, if slow, process. Novelist Jane Smiley became temporarily disabled after a horse-riding accident and, eventually, regained her lost function. In such cases, healing demands patience, energy, commitment, and a willingness to reduce or modify one's activities until the recovery is complete. The time spent on disability and recovery serves as an interlude, allowing the author an opportunity to delve deep into her physical vulnerability, her social status, her relationships, or her spiritual beliefs. As Smiley writes, 'One's injury powerfully attracts one's own attention' (p. 106). This much, at least, is true for all of the authors contained in this collection.

For the ill or disabled writer, such introspection can be ironic. From the time of onset of a disabling condition, the isolation imposed by immobility competes with the need for practical and/or emotional support. Mary Swander captures this dilemma in her essay 'The Fifth Chair.' She describes how, on the morning when she first woke up paralyzed with pain, she tried in vain to tell her friends and neighbors about her condition and about her desperate need for assistance. 'People had their own troubles,' Swander writes (p. 109). Friend after friend reacted with utter incomprehension, each one managing to steer the conversation toward his or her own concerns - taxes, a creaky house, anything but Swander's understated but earnest plea for help. She does finally get medical attention and treatment -though an accurate diagnosis would not come until many months later - but Swander must then adapt to her ongoing need for personal care assistance. This, too, she finds problematic, both for

herself and for those who provide her assistance.

These and many other essays offer important insights into the ways in which our culture respond to people who are ill or disabled - and into the ways that individuals, calling on their own strength and creativity, respond to illness or disability in themselves.

Gillam, Ronald B. *Memory and Language Impairment in Children and Adults: New Perspectives*. Gaithersburg, MD: Aspen Publishers, Inc., 1998, 244 pages, $35.00 softcover.

Reviewed by Venta Kabzems, Education and Behavior Programming Consultant, Edmonton Public Schools, Edmonton, AB, Canada.

This edited book is a treasure! Each chapter can stand alone, making the book a handy professional reference on topics relating to language and memory. The index is precise and useful as the chapters cover childhood through old age, congenital and acquired difficulties, theoretical and applied information.

The chapters in this publication appeared as articles in two issues of 'Topics in Language Disorders' in 1996 and 1997. They were extremely well received by members of our educationally oriented, multidisciplinary team including communication disorders, educational programming, occupational therapy, and psychology consultants; and by consultants for deaf and for visually impaired/blind students. From experience, the information contained in the articles/chapters has been extremely useful across a variety of professional disciplines.

The book is divided into two sections. Section I begins with a summary of current perspectives on short term and working memory. Subsequent chapters address the limitations of the models of working memory. Ways in which adults and children with language impairments are affected by difficulties with short term and working memory are described. Some chapters provide clinical examples, others outline assessment techniques, and several include reasonably detailed intervention protocols.

Section II describes long term memory systems (semantic, episodic, and procedural) and their effects on language. Long term memory systems are seen as substantially more capacious. They are directly affected by aspects of short term memory such as the attentional capacity devoted to the task, which has a subsequent impact on storage and recall of information.

Chapter after chapter underscores the role of memory in cognition. Specific chapters deal with the impact of a traumatic brain injury, language difficulties in dementia, and the effects of language impairment on the acquisition of academic skills such as learning to read. Helpfully, the chapters also outline intervention strategies, which make this a solid resource for practitioners in education, speech-language pathology, and other rehabilitation-related disciplines, including counselling-psychology, across the lifespan.

This tidy collection belongs on the shelves of educators, speech-language pathologists, rehabilitation practitioners, psychologists, families . . . anyone working with individuals with language impairments who wishes to have an impact on the functional communication of their students, clients, and patients.

Hagen, Chris. *Rehabilitation in Managed Care: Controlling Cost, Ensuring Quality*. Gaithersburg, MD: Aspen Publishers, Inc., 1999, 333 pages, $48.00 softcover.

Reviewed by Jae Kennedy, University of Illinois at Urbana-Champaign.

In the past five years or so, there have been a lot of analyses on the impact of managed care in medical and rehabilitative services. The basic message is something like: 'Look, stop whining and get used to it; managed care changes everything.' Hagen's new book, *Rehabilitation in Managed Care*, falls into this category. There is a slightly triumphant tone to these works - clinicians have had it too easy; they could talk big about patient welfare, take as much time and as many resources as they deemed necessary, and they could be paid handsomely for their efforts without worrying much about competition or demand. In other words, they were artificially shielded from the economic consequences of their practice. Now they have to join the rest of the service industry in dealing with profit and loss, and, quite frankly, it is about time.

The second chapter, 'The Business of Rehabilitation, Where Does All the Money Go?,'

with subheadings like 'Profit is Not a Dirty Word,' is probably the most overt expression of this managerial ideology. But, overall, *Rehabilitation in Managed Care* is a thorough and detailed guide on how to survive and even thrive in the brave new world of managed care. If I were a mid to upper level manager of a private rehabilitation facility, I would scrutinize this book and seriously consider using at least some client, process, family, and team management tools, which are described in great detail. As an academic and advocate, however, I find some of the content chilling. Take, for example, this discussion of insurance coverage: 'It is entirely possible that, on any given day, the team could evaluate several patients and determine that they all have the same diagnosis, type and severity of impairments and disabilities, and the same prognosis. The team must select different outcomes for each, however, because of differences in the health care coverage for each client or the client's family. The team, potentially, could believe it's been placed in an ethically compromised position and that the clients and their families could feel unfairly treated' (p. 95).

Feeling a little bad about telling young Johnny that, even though he could go back to high school with adequate rehabilitation, you can only get him to feed himself because his father enrolled in a cheapskate HMO? Relax, advises Hagen, 'It is extremely important that the team members bear in mind that the client's health insurance is out of their control and that they are functioning ethically within the constraints imposed upon them' (p. 95). In other words, they are only following orders.

Both providers and patients are rebelling against managed care because it reverses the traditional incentive of making money by providing care. The various patients' bills of rights all attempt to shift the balance back to service provision rather than cost containment. While those rights are unlikely to shelter patients from the market forces, the present form of the managed care revolution probably is not as permanent as Hagen and other folks believe.

Hamel, Ronald P., and DuBose, Edwin R., eds. *Must We Suffer Our Way to Death? Cultural and Theological Perspectives on Death by Choice*. Dallas, TX: Southern Methodist University Press (for the Park Ridge Center for the Study of Health, Faith, and Ethics), 1996, 355 pages, $35.00 hardcover, $18.95 softcover.

Reviewed by Paul K. Longmore, Professor of History, San Francisco State University.

These dozen essays, the editors' introduction, and religious historian Martin Marty's epilogue all examine physician-assisted suicide and euthanasia. A few contributors are physicians; most are theologians or religious ethicists. Half the essays operate from within Jewish, Catholic, and various Protestant theological traditions. All reflect on contemporary dilemmas of health care, particularly end-of-life care. Some contributors oppose legalizing physician-assisted suicide and/or euthanasia; some favor legalizing one or the other; some support the practice in restricted circumstances, but do not want it legalized.

'Disability' enters many of these essays, as it always appears in discussions of this issue. It emerges in several ways. As often occurs in this debate, some contributors lump terminally ill and chronically ill patients together as they consider pain and suffering and decisions about ending treatments and lives. This elision evidences the unconscious perception of disability as a form of dying or a living death. Some essayists reflect on the spiritual value of suffering. Again, they conflate disability and terminality. They also prescribe a social role that often has been imposed on people with disabilities: The saintly sufferer who literally embodies divine suffering serves as a role model of patience and faith, and exists as a vehicle of compassion so that others can work out their own salvation.

Writing in this vein, a Catholic theologian brackets disabled and dying folks as the 'diminished.' That perspective points to a third approach: Worrying about profit-oriented medicine, some contributors call for a more compassionate and equitable health-care system. They want sick and disabled people properly cared for. Thus, they view disabled people as (usually) passive objects of ministration. One essayist explains that, in the course of researching and writing his piece, he decided that he favors physician-assisted suicide. He was drawn to this conclusion by conversations with his aging mother who now walks with a cane she despises. One writer makes passing reference to disabled people's civil rights. Otherwise, this collection is devoid of knowledge or understanding of

disability rights or independent living.

Herr, Stanley S., and Weber, Germain, eds. *Aging, Rights, and Quality of Life: Prospects for Older People with Developmental Disabilities.* Baltimore, MD: Paul H. Brookes Publishing Co., 1999, 416 pages, $49.00 hardcover.

Reviewed by Kristine Mulhorn, Health Care Department, University of Michigan, Flint.

Aging, Rights, and Quality of Life is a text for its time -addressing the important issues facing older persons with developmental disabilities at a time when there is an emerging understanding of how rights and quality of life should be defined for this population. This is a comprehensive text, with complete coverage of issues facing this growing population, such as legal and financial considerations, quality of life, quality standards, models for support across the Western world, developments in public policy, managed care in the context of changes in the U.S. medical system, self-determination, self-advocacy, principles of good practice, and human rights requirements. The editors have compiled a textbook and handbook of these issues with a global perspective.

Aging is covered as a process affecting this population differently than others who are aging. Their needs are different and more complex. For example, as the life expectancy of this population has increased greatly, persons with developmental disabilities are outliving their parents and caregivers, and plans must be paid for future care and living. The rights of this population are addressed throughout the book with discussion of recent awareness and considerations of the rights of persons with disabilities. One example is the Vienna Declaration and Program of Action adopted by consensus. With discussions such as this and others that outline the content of laws in the U.S. and elsewhere that run throughout the edition, this is a reference source as well as a well-written text.

For example, protection and advocacy systems (P & As) are introduced as outcomes of the Developmental Disabilities Assistance and Bill of Rights Act of 1975. Quality of life, the final topic of the text, is also covered comprehensively. The authors point to the major challenge of the current care system: 'to strive for equity, empowerment, and inclusion of older adults with developmental disabilities' (p. 82). The authors consider how quality of life is measured and the special dangers of living with a developmental disability, which go beyond just ageism and include a greater likelihood of facing prejudice, discrimination, and neglect than those experienced by people without developmental disabilities.

Based on its format and content, this book should be required material in any course that includes discussion of this population. The significance of the growing impact of increased life expectancy among persons with developmental disabilities is the theme of the text, and I highly recommend this as a necessary library volume for persons in the field of disability.

Hodson, Barbara Williams, and Edwards, Mary Louise. *Perspectives in Applied Phonology.* Gaithersburg, MD: Aspen Publishers, Inc., 1997, 272 pages, $49.00 softcover.

Reviewed by Heidi M. Harbers, Illinois State University, Normal, IL.

This edited volume, the ninth contribution in Katherine Butler's 'Excellence in Practice Series,' provides a well-composed survey of key topics related to clinical phonology. Its cross-disciplinary (linguistics, speech/language science, speech/language pathology) contributors have all conducted applied phonological research. As a result, the reader gleans a polyocular view of phonology that not only bridges theory with practice, but also unites the past with the present and a look to the future.

The first three chapters provide some historical perspective before bringing the reader to current issues and applications. Chapters by Pamela Grunwell and Lawrence Shriberg assist the reader in understanding developmental phonological disorder. An additional chapter by Kim Oller discusses research issues. The final chapter by Barbara Hodson explores the evolution of phonological therapy and summarizes the Cycles approach, including metaphonological methods. Unique to this compilation is a brief, but thorough, explanation of non-linear phonology and a 40-page chapter by Joy Stackhouse about phonological awareness and the link between speech and literacy. The Stackhouse

chapter reminds the reader of the chronicity and change ability of phonological disorder in an individual's life.

This book is an indispensable resource for individuals who are new to phonology. Graduate students as well as practitioners will view this edited volume as a comprehensive introduction. Each chapter provides the reader with information to assist in understanding the field of clinical phonology. It includes a glossary of terms and an extensive reference list.

For those already familiar with phonology, it will become an often utilized reference bringing them up-to-date on issues in phonology that continuing education introduced, but did not fully explore. Experienced practitioners will welcome chapters by Grunwell, Shriberg, Stackhouse, and Hodson that provide useful information to enhance clinical problem solving.

I use this book with satisfaction as a researcher, a clinician, and a professor with graduate students. Speech-language pathologists at all levels will find value in its pages.

Kane, Stephanie. *AIDS Alibis: Sex, Drugs and Crime in the Americas.* Philadelphia, PA: Temple University Press, 1998, 232 pages, $59.95 hardcover, $19.95 softcover.

Reviewed by Charles D. Palmer, Ph.D., Mississippi State University.

AIDS Alibis is an excellent ethnography of HIV, AIDS, and the behaviors of a particular social class of people. The social systems where AIDS and the HIV virus are most prominent (and most visible) - the world of social marginalization characterized by prostitution, drugs, and crime - are explored with an openness and candor that is rarely experienced outside the real life circumstances in which they occur.

The author has certainly captured the corporeal intensity of living and dying with AIDS within a subculture of modern society. The reader is offered a graphic picture not simply of unfortunate people who are down on their luck, but, in most cases, people who have participated in actions that have led (or pulled) many into lives fraught with pain and suffering. While including references to contracting the HIV virus through blood transfusion and other (accidental) means, the author provides a detailed description of the lives of people who exist in a world typified as socially deviant who have contracted the disease as the result of ignorance, over-confidence, or, in some cases, overt maliciousness. What the reader will experience in this work is the gut-wrenching reality of selling one's sexual activities to fund drug-induced mental escape, carelessness that comes as a result of participating in a life with nothing left to lose, or the callousness and depravity of individuals determined to avenge themselves upon the world for perceived injustices.

What you may not find in this work is a goal, a concrete outcome. What is the intent of this work? If the goal is to inform the readership to an ethnographic reality, the book certainly succeeds in this respect. If the goal of this work is to provide impetus for social change, as this reviewer infers from the introduction, the vast majority of the book simply establishes a vivid back drop without providing a structure or direction for social/governmental evolution. How exactly would the author suggest implementing the vague societal changes? To call for change without providing details for such change detracts from the effectiveness of this work. As we have witnessed in the past, recognizing the need for change requires no significant insight - solutions on the other hand. . .

Lang, Harry G. *Silence of the Spheres: The Deaf Experience in the History of Science.* Westport, CT: Bergin & Garvey, 1994, 187 pages, $49.95 hardcover.

Reviewed by Martha L. Edwards, Assistant Professor of History, Truman State University, Kirksville, MO.

The meticulously-researched *Silence of the Spheres* brings dozens of deaf and hearing-impaired scientists out of obscurity. Lang, a Professor of Educational Research and Development who is himself deaf, set out to write about neither Deaf culture nor the history of science, but rather about the intersection between science and deaf people. Lang's main goals are to present the accomplishments of deaf people in science and to help break down the attitudinal barriers that remain against the participation of deaf people in the scientific community. The former goal is met. The

application of Disability Studies, particularly Disability History, would have served Lang well in meeting his second goal.

The book is organized chronologically into five chapters, from the Enlightenment through the Modern Era. Lang provides synopses of the careers of a wide range of deaf scientists, ranging in prominence from the 'Silent Angels" deaf nurses in the early Twentieth Century, to such household names as Thomas Edison.

Lang acknowledges deaf people as a minority group that faces discrimination, but little is done with this reality as a historical entity. The cultural construction of deafness is never addressed, and so Lang's work is historical only in that it deals with the past. If attitudinal barriers are to be broken down, showing the accomplishments of people with disabilities is not enough. Scholars must acknowledge not only the history of deaf individuals but, also, of deafness itself. At the heart of Disability History is the principle that deafness - and all disability - is not a static, inherent phenomenon but, rather, is shaped by its cultural context. Lang laments the dearth of a record of deaf people before the Sixteenth Century, but this very dearth, because it suggests a lack of categorization and definition of deafness, might have provided an excellent point of entry into the convergence of deafness and science.

Lang skillfully reaches his main goal, to bring deaf scientists out of obscurity. I hope that this responsible and well-researched piece of scholarship is not the final word on the confluence of deafness and science, but, rather, that it will be used as a base from which to launch an investigation from the perspective of Disability History.

Leigh, Irene W., ed. *Psychotherapy with Deaf Clients from Diverse Groups*. Washington, DC: Gallaudet University Press, 1999, 290 pages, $65.00 hardcover.

Reviewed by Cynthia J. Nickless, Deaf Wellness Center, University of Rochester Medical Center, Rochester, NY.

Irene Leigh has accomplished the challenging task of editing a well-written and much needed book on the provision of effective psychotherapy to the richly diverse Deaf population. Diversity in the Deaf community is as complex and varied as that of any large subculture of our country. Recognizing that diversity in the Deaf community not only encompasses ethnicity, sexual orientation, and gender, Leigh has attended to additional characteristics of difference that warrant a significant level of clinical acumen, including Usher Syndrome and HIV/AIDS. Furthermore, this book recognizes that serving deaf persons with histories of sexual abuse, chemical dependency, or functional limitations requires that the clinician not only be skilled at serving deaf individuals, but also that she or he be able to integrate current theory and clinical innovation relevant to specialized topic areas.

This book is unlikely to collect dust on the bookshelves of responsible therapists, regardless of their experience with serving deaf persons. It will serve as a riveting and enlightening instructive manual for psychotherapists who know little to nothing about serving deaf individuals. For established professionals in mental health and deafness, this book serves as a testimony to the necessity of maintaining a generalist orientation. Specifically, those of us who serve deaf consumers are all too aware of the necessary level of clinical skill and the breadth of knowledge that is required in effectively serving this heterogeneous population.

Certain chapters of this book are especially noteworthy, including Tovah Wax's brilliantly written chapter on the evolution of Deaf women. In addition, Ilene Miner has made a significant contribution to our understanding of clinical practice with individuals with Usher Syndrome.

In conclusion, this is a must-have text that offers numerous clinical vignettes and practical suggestions for the therapist who is committed to serving deaf consumers.

McClannahan, Lynn E., and Krantz, Patricia J. *Activity Schedules for Children with Autism: Teaching Independent Behavior*. Bethesda, MD: Woodbine House, 1999, 128 pages, $14.95 softcover.

Reviewed by Larissa Burford, University of California, Berkeley.

The goal of this book is to introduce activity schedules to parents and teachers who have children with autism. It offers descriptive suggestions on how, step-wise, to teach independence. The book thoroughly details each step, covering many trouble-shooting techniques, and also answering commonly asked questions.

Detailed explanations seem necessary for developing a different way to teach. However, the thoroughness of the explanations can get redundant at times. The explanations are geared more for the parent than for the professional. The average person can read the book and develop activity schedules for their children. The scope of the book is limited to activity schedules. This makes the book clear and precise. The format suggested by the authors seems to be an effective plan for implementing choice and independence for those with autism. The benefits of the schedule help to integrate the disabled child into task-oriented engagements. Social interaction is developed within the schedule.

Integrated into the text are stories of success. These personal highlights keep the reader interested. They show the effectiveness of the program, encouraging parents and teachers to stick with the procedures. The stories are diverse in showing various levels of autism and relative success for each individual. The scope of the book effectively integrates the activity schedule procedure so that a child of almost any age and ability will be involved actively. It is obvious that the authors are experienced and have greatly researched their technical procedures. The subtitle of the book, *Teaching Independent Behavior*, accurately describes the goal of the book's suggested schedule use with people who have autism. This book should be recommended to everyone who works with people with autism.

Morris, Robert, Caro, Francis G., and Hansan, John E. *Personal Assistance: The Future of Home Care.* Baltimore, MD: The Johns Hopkins University Press, 1998, 224 pages, $48.00 hardcover, $18.95 softcover.

Raymond E. Glazier, Ph.D., Associate, Abt Associates Inc., Cambridge, MA; and Manager of Abt's Center for the Advancement of Rehabilitation and Disability Services. (The reviewer's dissertation, 'Preference for Consumer Directed Personal Assistance Services' [1999] is available in hard copy or on microfiche from UMI, P.O. Box 1346, Ann Arbor, MI 48106 [no. 9933827]; or on diskette from <ray_glazier@abtassoc.com>.)

The two senior authors of this book come from the Gerontology Institute of the University of Massachusetts, and Morris draws heavily from his prior Brandeis University research on PACE (Program of All-inclusive Care for the Elderly) and SMOs (social maintenance organizations). Thus, this broad-ranging examination of home and community-based long-term care policy is well grounded in and informed by considerable expertise in elderly home care issues. To the extent to which the concerns of elderly disabled people and non-elderly disabled people are synonymous, readers involved with either constituency will find this policy discussion quite valuable.

Of particular interest is the authors' survey of the historical context of home and community-based long-term care from total reliance on family and individual charity in early Western civilization, through the local public authority embodied in the poorhouses established by the late 16th Century Elizabethan Poor Law, and up to the present social welfare system. Throughout modern history, home care has been defined as a medical need and provided in a social welfare context. Ironically, in the present day United States, Medicaid long-term care is part of a program originally designed to meet the health care needs of poor people, but it has become a middle-class entitlement to publicly-funded nursing home care (or home and community-based care) once individuals have divested themselves of assets and 'spent down' to indigent status.

The combination of the aging trend in the general population, which actually began with the Industrial Revolution, recent medical advances that allow greater numbers of younger persons to survive devastating injury or illness with severe disabilities, and the family-fracturing effects of modern day geographic mobility have conspired to expand the need for home care and to make its provision more problematic. The authors survey the health care policy scene, managed care, and cost containment efforts in the context of the present conservative political climate and conclude that

traditional home health agency services will be either supplemented or supplanted by personal assistance if public funding for it is developed.

In their review of options for improving the financing of long-term care in general (and personal assistance in particular), Morris et al. examine first the role of federal programs, noting that Medicare, even though it now covers much more of home health care services than previously (through certified home health agencies only, and for homebound persons only), is quite limited and accounts for less than half the total health care expenditures of elderly people. Medicaid benefits vary from state to state, and long-term care services account for 36% of total Medicaid expenditures (1994), financing 40% of all nursing home care in the nation. There are large holes in both safety nets.

Given all of the constraints, public insurance funding has seemed to others to be the only option. However, the authors conclude: 'A social insurance model that would provide universal or near universal coverage for some aspect of long-term care is highly unlikely in the current political climate' (p. 163). 'Most feasible in the current environment is more extensive private financing of long-term care' (p. 164). But one problem with private insurance financing of long-term care is that young people, who could purchase long-term care insurance at low level premiums, are oblivious to the need for it until they have aged to the point where premiums become prohibitively expensive in later life. Even those who do purchase it often let their policies lapse.

Out of pocket payment for long-term care can be facilitated for the landed gentry by reverse mortgages, which allow homeowners to draw down their home equity almost like an annuity. Public insurance could be combined with private insurance by publicly subsidizing premiums for indigent persons. If the private insurance were so structured and marketed to appeal to the huge middle class, to whom could be added the low income persons with subsidized policies, the risk pool would be quite large. Yet the generational problem that plagues Social Security holds for any form of public insurance for an age-linked risk: The Baby Boomer bulge in the population concentrates the pay-out at the time when premiums are being paid in by fewer younger persons. Nevertheless, it is possible to adjust premiums to anticipate and compensate for the shift in balance of program funds.

Readers coming to this book from a disability activist perspective may be dismayed by the politically incorrect use of terms like 'the disabled' or, worse yet, 'the handicapped' in early chapters. And even those in the disability movement who are themselves aging often reject this book's assumption of a consonance of interest between the aged and disability communities. Moreover, they may find puzzling the complete absence of mention of MiCASA (the Medicaid Community Attendant Services Act of 1998, recently renamed MiCassa to reflect the inclusion of 'and Supports' in the title). While the omission may seem no more than a reflection of the authors' concentration on the elderly population to the exclusion of younger persons with disabilities, one must keep in mind that *Personal Assistance: The Future of Home Care* was written prior to the introduction of MiCASA in Congress and its publication in 1998.

This reviewer would like to see published, perhaps as a *Disability Studies Quarterly* article, the authors' studied reaction to MiCassa and evaluation of its prospects in the context of their previous research and the public policy considerations with which they are so conversant. First, they would need to absorb some of the extensive disability literature on personal assistance services (PAS), much of it from the World Institute on Disability. (See <http://www.wid.org/>.)

Pawluch, Dorothy. *The New Pediatrics: A Profession in Transition*. New York, NY: Aldine de Gruyter, 1996, 175 pages, $41.95 hardcover, $24.95 text (10 or more copies).

Reviewed by Laurence J. Ronan, M.D., Combined Internal Medicine/Pediatrics Residency Program, Harvard Medical School-Affiliated Hospitals.

Dorothy Pawluch's short book, *The New Pediatrics*, smacks head on into some of the longest, most contentious controversies in medicine. It is well worth the read by both the medical and non-medical person, partisan or simply interested.

The public likely does not know much about the ongoing saga of pediatricians trying to win professional respect from adult medicine and surgical colleagues, the self appointed queen and king

of the health care realm. (If respect is partially measured by money, take note that pediatricians are the lowest paid physicians on average in this country.) Once the antibiotic era and prevention decades conquered polio, pertussis, tuberculosis, bacterial pneumonia, scarlet fever, and dysentery, the pediatrician turned to the 'new pediatrics' - behavioral, social, and developmental issues within the patient and community.

In a time of aggressive technology and basic science advancement, however, 'real doctors,' i.e., those whose incomes, professional careers, and status depend on the new biotechnologies, look down on their pediatric colleagues as practicing a less complicated, less academic medicine. The implication, of course, is counter to a healthy populace and just plain dumb: Is stopping a young person from smoking, identifying key learning disorders that can be remedied, or preventing a child from going through a windshield any less important - or, indeed, less intellectually challenging - than treating coronary artery disease or removing a gall bladder? Some think that he/she who figures out how to prevent a child from becoming pregnant, in fact, deserves the Nobel Prize.

The New Pediatrics adequately chronicles the at-times nasty commercial struggle waged by general pediatricians to survive in a market place oversupplied with competing caretakers for children - family physicians, adolescent medicine specialists, internists, nurse practitioners, and, indeed, pediatric and adult subspecialists. Presently, only 50% of all office visits by 0-17 year olds are to pediatricians. The Federation of Pediatric Organization's Task Force on Pediatric Education, formed in 1995 to deal with medical school and residency training, clearly has its eye on increasing the pediatrician's share of the pie with its recommendation that 'all children should receive care through a medical home in which the pediatrician is the coordinator of care.' Battle lines are drawn, and public relations skirmishes have broken out; we can expect an escalation in hostilities shortly.

The book really does not deal with the fundamentally political question of how much of the country's resources our children deserve (a companion issue to the national debate over what kind of educational infrastructure we should create). Nor does it address in any meaningful way two key assumptions of the pediatric opposition: 1) that less specialized generalists will take adequate medical care of children; and 2) that consumers -parents - will accept less specialized care for their children. Finally, the book ends in 1996, and the world of medicine has changed even since then. The fate of pediatrics may lie in important cultural trends as more women become doctors and reshape the profession around part-time work and family focus. And, pediatric education hinges on national strategies on financing graduate medical education yet defined. Look forward to a sequel to *The New Pediatrics.*

Perkins, Lanny, and Perkins, Sara. *Multiple Sclerosis: Your Legal Rights* (2nd Ed.). New York, NY: Demos, 1999, 227 pages, $21.95 softcover.

Reviewed by Charles D. Goldman, Esq., Private Practice Attorney, Washington, DC; formerly, first General Counsel of the Access Board.

I wanted to like this book, especially at its affordable price. If your issue is Social Security Disability Insurance (SSDI), then, this book may be worth purchasing. Otherwise, it is too simplistic and not realistic on discrimination issues.

The authors make it easy for the average person with a disability (or, on his/her behalf, family/friends) to apply for SSDI benefits. The forms reprinted are very helpful. However, when you devote more than a third of a book to such forms (78 pages), there is not too much room left over to address issues. Sadly, their good work came out too early to pick up the Supreme Court decision that now allows a person with a disability to apply for SSDI as well as to maintain cases for denial of equal employment opportunity. But, by devoting such disproportionate attention to this one issue, the authors devalue all the other laws and legal rights.

The authors are also very good in describing the roles of doctors and lawyers. Their first chapter is an excellent start. But the authors fail to advise that doctors commonly need lead time to write statements as well as a position/job description to help support their views. Make it easy for the doctor and the lawyer to help the person with a disability.

The authors' treatment of discrimination issues (employment, public services, public ac-

commodations), including the Americans with Disability Act, is basic and somewhat disjointed, with enforcement provisions not always near the descriptive provisions. The authors fail to note that state laws that are stronger than the ADA are not superseded by the ADA. State laws are particularly important when you have smaller employers who are not covered by the ADA. Also, certain jurisdictions, such as the District of Columbia, have mandatory alternative dispute resolution (mediation), which is a quick, inexpensive way to resolve a complaint. The authors note the role of the EEOC and the Department of Justice in enforcing the ADA, but they fail to acknowledge that the cases that the agencies actually litigate are a very small fraction of the complaints filed, and that, as a practical matter, in all likelihood, an attorney will have to be retained if the individual wishes to go to court.

The points about SSDI and the initial chapter on doctors and lawyers make the book worth the price for organizations and for individuals with disabilities (not only multiple sclerosis). However, a civil rights text it is not.

Stenross, Barbara. *Missed Connections: Hard of Hearing in a Hearing World.* Philadelphia, PA: Temple University Press, 1999, 151 pages, $39.50 hardcover, $16.95 softcover.

Reviewed by John Christiansen, Department of Sociology, Gallaudet University, Washington, DC.

According to Barbara Stenross, *Missed Connections* is the story of how a few sounds missed in conversation can lead to subsequent problems in communication. Stenross spent several years in the early 1990s attending meetings of a North Carolina chapter of SHHH (Self Help for Hard of Hearing People), and much of the information in the book is based on interviews with participants at these meetings as well as on her own participant observation. Although Stenross is identified as someone who teaches sociology, there is little sociological analysis in the book. Rather, the book is apparently written for the general reader. Unfortunately, the book is not organized very well, and practical suggestions that might appeal to hard of hearing people are often lost in chapters that are frequently too superficial for serious readers.

While, overall, the book is disappointing because it lacks both a depth of analysis and a breadth of coverage (just over 100 pages of text), there are a few chapters that contain information hard of hearing people, and people who associate with hard of hearing people, might find useful. There is a discussion of assistive listening devices that is interesting, although some illustrations would have added much to the discussion. Another section dealing with tips for coping with a hearing loss is also useful, as is a list of selected resources at the end.

Another problem with the book is that, perhaps, the most important new technological development in recent years, a multi-channel cochlear implant, is mentioned only in passing. While an implant is likely to be considered only by those who are very hard of hearing (severely to profoundly deaf), there are nevertheless many people depicted in the book who would appear to be good implant 'candidates.' There appears to be at least a five-year interval from the end of the actual fieldwork to the publication of the book, and this makes for a somewhat dated manuscript.

Swindells, Julia, ed. *The Uses of Autobiography.* Bristol, PA: Taylor & Francis, Inc., 1995, 238 pages, $21.95 softcover.

Reviewed by Patrick McDonagh, Concordia University, Montreal, Quebec, Canada.

The essays in this collection range from the focussed analysis of particular narrative autobiographies to broad sociological case studies taking data from such sources as the Mass Observation Archive from the 1920s and 1930s. The diversity of material is united by a consistent attempt by the authors to depart from 'mainstream' autobiographical narratives of an independent person, usually male, who successfully individuates himself from the world around him. Rather than seeing autobiography in its traditional role of a narrative that imposes order on the chaos of a particular life, the writers represented here seek to find new applications of autobiography - as documents of social history, as emancipatory cries, as struggles to stabilize threatened identities - and to draw on marginalized sources: Victorian women, African-American survivors of slavery, and working-class men and women.

If another constant could be deduced, it is this: Each essay seeks to map the strategies used by the writer to negotiate her or his tenuous social position. This volume was developed from papers presented at a 1994 Cambridge conference (the source material is overwhelmingly British), and the chapters represent not so much polished comprehensive analyses, but short works-in-progress, often raising more questions than they answer. Also, the focus tends toward the specific rather than the general - that is, plenty of case studies, little theory. If this is a weakness, however, the staccato bursts of analysis also provide the volume's strength: They demonstrate the many applications of autobiographical criticism in all its hues and shapes. Therein lies its interest to the Disability Studies scholar who draws on autobiographical sources (and who does not at some time or another?). Because these essays consistently focus on marginalized populations, they also deal with issues analogous to those informing the autobiographies of people with disabilities: individual prejudice (overt or covert), systemic barriers to social participation, and a 'devalued' cultural identity, among others. This should not be the only book of autobiographical criticism on the shelf of someone working in Disability Studies - but it is a worthy addition to any collection.

Walker, Leslie C., Bradley, Elizabeth H., and Wetle, Terrie, eds. *Public and Private Responsibilities in Long-Term Care: Finding the Balance.* Baltimore,MD: The Johns Hopkins University Press, 1998, 224 pages, $42.00 hardcover.

Reviewed by Debra Sheets, Andrus Gerontology Center, University of Southern California, Los Angeles, CA.

A number of books in recent years have examined some of the political, social, and economic factor affecting the organization and financing of long-term care. *Public and Private Responsibilities in Long-Term Care* complements the literature and stimulates additional discussion of this important topic, which affects nearly one million Americans. This edited volume brings together a distinguished group of contributors who examine the intersection of public and private responsibilities in financing long-term care and illustrate the complexities of developing politically feasible and socially acceptable public policies to address long-term care needs.

The book is divided into four sections. In the first section, Robert Binstock provides an introduction and overview of the structure of long-term care that provides a foundation for the following chapters. The second section presents a theoretical context for public and private roles in long-term care from the disciplines of political science, economics, sociology, and philosophy. In these chapters we gain an appreciation for the importance of social norms; an understanding of the relevant principles of welfare economics; a recognition of the importance of race, ethnicity, and cultural factors; and insight into the individual and societal obligations to make provisions for long-term care.

The third section reviews current policies and programs for financing long-term care. These chapters describe a number of programs in which public and private partnerships have developed to address the need for long-term care. The excellent concluding chapter by Walker and Bradley integrates the theory, policy, and practice issues identified in preceding chapters. The authors identify common themes of responsibility, discuss how theory and practice can be integrated, and consider future issues that will affect policy development and the financing of long-term care.

This volume highlights the value of a cross-disciplinary approach to social policy issues and will be useful to anyone interested in the organization and financing of long-term care. The main limitation of the book is that it focuses primarily on issues involving the long-term care of older adults, even though working-age adults account for 40 percent of the long-term care population.

Ziegler, Edward, and Bennett-Gates, Dianne, eds. *Personality Development in Individuals with Mental Retardation.* New York, NY: Cambridge University Press, 1999, 304 pages, $64.95 hardcover, $24.95 softcover.

Reviewed by Timothy Lillie, Ph.D., Department of Counseling and Special Education, The University of Akron, Akron, OH.

When I first came into the disability field, it was through direct service in a community

residential program for adults with mild to moderate retardation (as the terms were then defined). I remember being pleasantly surprised to find that the people with mental retardation with whom I worked had distinct and distinguishing personalities; differed in their interests (most of which were age-appropriate, though a few were not); and tried to behave, as much as they were able, like everyone else. Of course, I had imbibed the idea that mental retardation meant dullness, lack of affect (or too much), a sort of 'animalness,' and all the rest of what we now know to be plain wrong. But I had no experience or training when I began - just the phone number of my boss in one hand and Wolf Wolfensberger's *Normalization* in the other hand.

As a result, I treated the people with whom I worked in the only way I knew - just like everyone else, except maybe needing a little help in some area of their lives. In fact, staff were encouraged to find ways to help individuals learn how to shop appropriately, how to handle their money, how to date, and so forth. Later, when I heard about 'social construction' of disability and the need to move from academic skills instruction to 'functional skills' training, I was ready to accept both concepts quickly because I had lived with and worked with people who had been long-term and, in one case, continuing victims of discrimination based on the attitude that 'mental retardation' could only be understood as a cognitive impairment. In fact, local psychiatrists refused to treat people with mental retardation, holding they would not 'benefit' from treatment.

One young man with whom I worked was deliberately infantilized and made dependent by an older man who saw the younger one as a son-like figure. He thought he was helping the young man, but, in fact, he hurt his life terribly. Again, he based his actions on the notion that cognition is all there is to mental retardation: If the IQ is not there, he reasoned, the individual cannot be other than dependent and child-like. Although I knew (intuitively, then) that he was mistaken, and, although I tried to change his mind, I lacked the credentials or the experience to do so.

Many years later, along comes *Personality Development in Individuals with Mental Retardation*, edited by Edward Ziegler of the Yale Child Study Center, and Dianne Bennett-Gates of Cardiff University, which spells out in exhaustive detail a compelling case that cognition alone is <u>not</u> enough when discussion of mental retardation is the subject. Motivation, personality, expectancy of success (or failure), outer directedness, and other elements in the ecology of the individual with mental retardation are at least as telling in terms of the outcome for the individual as the IQ score and scores on adaptive behavior assessments.

In short, people with mental retardation are more <u>like</u> typically-developing people than unlike them. Ziegler and Bennett-Gates have done more than just assert the developmental approach (as opposed to the perspective that the development of individuals with MR is 'different,' somehow, than that of typically-developing people); they have backed it up in this book with waves of well-designed reported studies examining the development of people with mental retardation. This book could be of great use in the classroom (probably at the graduate level) and would serve as a useful reference book for people working in community settings, especially when teaching social skills.

Zionts, Paul, ed. *Inclusion Strategies for Students with Learning and Behavior Problems: Perspectives, Experiences, and Best Practices*. Austin, TX: Pro-Ed, 1997, 424 pages, $36.00 softcover.

Reviewed by Keith Storey, Associate Professor of Education, Chapman University, Concord, CA.

This book provides an overview of inclusive education strategies, with a focus on classroom implementation. Up front, the book nicely outlines basic terminology of least restrictive environment, integration, inclusion, mainstreaming, and the regular education initiative. Unfortunately, the chapter authors do not always follow these definitions and sometimes confuse mainstreaming and inclusion in classroom examples ranging from segregated special education classes to inclusion classes. Generally, the chapters do provide fairly detailed information on 'how to' teach in inclusive settings, and they provide real life examples of what often works or does not work.

There is an innovative chapter on how to develop program elements supportive of teachers and students that provides examples of how to set up appropriate support systems and how to draw supports

from community services and agencies. There is an excellent chapter on academic equalizers and learning enhancers, which should be very beneficial for teachers. Throughout the book, there is a wealth of information on how to teach on a day-to-day basis and how to structure lessons. Another nice touch of the book is that there is a very insightful personal viewpoint chapter by a student with a disability.

With the focus on behavior problems, there are three chapters devoted to classroom management and behavior supports. The chapter on inclusion and diversity also provides a good description of how to set up a classroom environment. Teachers should be able to draw on these chapters for many techniques for dealing with behavioral challenges in classroom settings. A key point in one of the chapters on behavioral support, and a rule that teachers should always remember, is that, if what you are trying is not working, then try something else. Weaknesses of these three chapters are that there is minimal discussion of functional analysis of challenging behaviors, and the use of aversive interventions is sometimes promoted.

In summary, this is a good resource to help teachers understand inclusive settings and, more importantly, how to teach in inclusive classrooms. Though the book sometimes lacks a specific focus (examples provided in chapters range from behavioral disorders to learning disabilities to cerebral palsy to multiple disabilities), there is much valuable information presented in a practical manner.

Books for Kids

Kent, Deborah. *Why Me?* New York, NY: Scholastic, Inc. (555 Broadway, New York, NY 10012), 1992, 190 pages, $3.50 (U.S.) softcover, $4.50 (Canada) softcover.

Reviewed by Sieglinde A. Shapiro, Coordinator, Disabilities Studies, Institute on Disabilities, Pennsylvania's University Affiliated Program at Temple University.

The cover notes for this paperback aimed at 10-14 year olds describe the dilemma faced by the main character, Rachel, who 'wakes up one morning to find her world has been smashed to smithereens. Her whole body feels heavy and painful, and she can barely sit up. Rushed to the hospital, she learns that she has a kidney disease. Rachel will have to be on dialysis for the rest of her life . . . or until an organ donor can be found.' The plot is further complicated by the fact that Rachel is adopted. The book explores a year in Rachel's life as a typical 13-year-old, who must deal with chronic disease and find her birth mother.

As one who has dealt with chronic kidney disease my entire life, I was interested to see how this issue would be addressed in a book aimed at adolescents. I was fairly impressed with the level of information that was provided regarding the particular type of kidney disease Rachel contracts (Henoch Schonlein purpura or HSP), the symptoms she encounters, and how CAPD (continuous ambulatory peritoneal dialysis) works. Kent also does well exploring the feelings and emotions the main character and her family members experience as a result of dealing with the many issues that arise.

The major problem I had with Kent's writing was that her first-person account as the character Rachel did not ring true. The story was being told from a 13-year-old child's perspective, but it came across as an adult trying to write and speak like a child, but who failed to do so. Kent would throw in an occasional 'cool' or 'gross' or 'eew' in Rachael's speech, but, for the most part, the dialogue and the analysis of feelings and events sounded too adult.

The other problem with the story was the all too predictable happy ending. Rachel finds her birth mother, who is not only beautiful, sophisticated, and a successful business executive, but is also anxious to donate her kidney because 'it makes everything complete for me somehow' (p. 157). Perhaps 10-14 year olds need such an ending. I felt that it gave false hope and a saccharin conclusion to what was a fairly informative read.

Film Clips

Churchill, Jack (Producer/Director). *Recovering from Mental Illness* [video]. Hohokus, NJ: Mental Illness Education Project Videos (22-D Hollywood Ave., Hohokus, NJ 07423; 1-800/343-

5540), 1997, 27 minutes, $68.95 institutional purchase, $38.95 family member purchase.

Reviewed by Rosalyn Benjamin Darling, Indiana University of Pennsylvania.

This video is one of a series of three tapes about a young woman named Bonnie, who is recovering from paranoid schizophrenia. The viewer sees conversations involving Bonnie, a social worker, and Bonnie's sister and parents. The tape is divided into a series of segments that relate to issues of hearing voices, separating the person from the illness, accepting the illness, acknowledging that recovery is drug dependent, understanding the role of expectations, and recognizing recovery. Bonnie is a personable and articulate individual, and her openness in discussing her experiences is refreshing. Her family members also speak frankly about their reactions to the illness experience and provide insight into the kinds of stresses that families face in such situations. Bonnie's mother seems in some ways to be a model parent - completely accepting and supportive. I suspect that such strong family support has been instrumental in Bonnie's successful efforts to reestablish control over her life.

The tape provides a good overview of the issues it covers, but it does not provide much depth in relation to any of them. I think the video would be useful in an undergraduate course on mental illness or on general disability issues, especially one taught from a psychological perspective. The material would also be an excellent discussion starter in a support group of persons with mental illness and their families.

As a sociologist, I was a little disappointed that relationships with people outside of the family were not really addressed. At the very end of the tape, Bonnie mentions the continuing stigma of being an ex-mental patient. I would have liked to have seen more discussion of this issue, but the tape ends rather abruptly without any discussion of it at all. On the whole, though, I enjoyed and learned from this video. By the end, I was really rooting for Bonnie and hoping for her continued success.

Churchill, Jack (Producer/Director). *Recovering from Mental Illness* [video]. Hohokus, NJ: Mental Illness Education Project Videos (22-D Hollywood Ave., Hohokus, NJ 07423; 1-800/343-5540), 1997, 27 minutes, $68.95 institutional purchase, $38.95 family member purchase.

Reviewed by Christine C. Hubbard, MA, OTRL, Fieldwork Coordinator, Masters in Occupational Therapy Program, Lewiston-Auburn College, University of Southern Maine.

The video *Recovering from Mental Illness*, one of 'The Bonnie Tapes' series, provides a family perspective on the process of managing and living with the symptoms of a major mental illness. Bonnie, her parents, and her sister share their views and understanding of how Bonnie's psychotic disorder disrupted their daily lives and their relationships. Though the title does include the idea of recovery, the family focuses more specifically on how the symptoms of the illness have been managed, both on a daily basis and over the course of the past decade. The video illustrates the need for education about how symptoms of the illness affect behavior, relationships, and daily function. Bonnie successfully describes the effects of her illness on her life. It appears that her understanding is the result of a long process of living with and coming to terms with an illness that can have confusing and demoralizing symptoms.

A video of this nature would be a helpful educational tool for individuals and families who are learning to live with and manage a major mental illness. It carries a critical message about understanding the difference between the symptoms of an illness and the person experiencing the symptoms. The two are very different, but they can be confused and may be thought to be one and the same at times. Viewing the video would also be beneficial for people who plan to work with individuals diagnosed with mental illness. Bonnie's story helps to remove the judgment and stigma often associated with mental illness. Bonnie and her family do an exceptional job of describing how her mental illness has affected her daily activity and life roles, and what part motivation and self-control play in her ability to function independently.

'The Bonnie Tapes' series is available for further viewing of how the issues around mental illness have affected Bonnie and her family, their relationships, and their lives.

Kaufman, Thomas (Producer). *See What I'm Saying* [video, open captioned]. Boston, MA:

Fanlight Productions (4196 Washington Street, Suite 2, Boston, MA 02131; 1-800/937-4113), 1992, 31 minutes, $195.00 purchase, $100.00 rental/week, $50.00 rental/day.

Reviewed by Richard W. Meisegeier, Ph.D., Gallaudet University, Washington, DC.

This CINE Golden Eagle award-winning documentary follows four-year-old Patricia, the only deaf member of her Spanish- speaking family, through her first year at Kendall Elementary School at Gallaudet University. Early scenes of Patricia at home and at school illustrate her feelings of isolation, frustration, and anger at not being able to communicate with her family, teachers, or peers. These are authentic in nature and not contrived to prove a point. Patricia's family's response to her behavior is also very typical. There is a sense of love and caring, but also of frustration with their inability to communicate with her. The impact of deafness is clearly multi-faceted.

The documentary includes vignettes with successful deaf adults and with Alicia, now a teenager, who has hearing parents who have learned to communicate with her using sign language. Both Alicia's mother and father are candid about the struggle they went through to come to the point of accepting Alicia's deafness, and sign language as a way to communicate with her. A variety of signing modes ranging from preschoolers doing 'baby talk' in signs, to ASL (American Sign Language), to English-based signing is shown. There is no attempt to 'favor' one mode over the other. Rather, the message is the need for communication between child and parent, child and teacher, and child and peers. The advantages of using signs are obvious. At the same time, the importance of speech training is not ignored.

The documentary accurately portrays the challenges hearing parents face with their deaf child. It does not hold out false promises, but, realistically - though necessarily in capsulated form - it shows the frustration and anger of the child, the hopes (realistic and not so realistic) of the parents, the coming to grips with what is, how others have coped with deafness, and what possibilities lie ahead.

Young, Donald (Producer/Director). *Raymond's Portrait: The Life and Art of Raymond Hu* [video]. Boston, MA: Fanlight Productions (4196 Washington Street, Suite 2, Boston, MA 02131; 1-800/937-4113), 1997, 27 minutes, $195.00 purchase, $50.00 rental/day.

Reviewed by Laurie R. Lehman, Long Island University, Brooklyn, NY.

Raymond's Portrait: The Life and Art of Raymond Hu tells the story of a 19 year-old Chinese-American man with Down syndrome who develops into a talented and popular brush painter. The film interweaves interviews with Raymond, his parents, his younger brother, and his art teacher, and striking illustrations of his paintings of animals. His mother, Margaret Hu, explains at the beginning that, since parents in the Chinese culture hope their sons will become dragons, or successful in life, they were disappointed about Raymond's 'condition' when he was born.

This documentary's strength rests in the truths expressed by Raymond and his family and in their honesty about his development. Although Raymond's speech is difficult to understand at times, his intelligence and maturity are always noticeable. Most of the video examines his progress as a painter, showing many examples in great detail of animal faces with eyes that are searing and powerful. We see Raymond at his first art show describing his surprise and pleasure that his work prompted a woman to cry. Art lovers may be fascinated with his pictures as reflections of a growing emotional sophistication and depth - from bright, clearly etched lines of happy animals to darker, more soulful renditions.

Nevertheless, the story of Raymond Hu may also play into the hands of those with misconceptions about people with disabilities. Because success such as Raymond's challenges negative stereotypes, people may avoid facing their own prejudice through other inaccuracies. In Raymond's case, artistic ability could be wrongfully interpreted as compensation for his disability, compensation that comes to those who cope with adversity. When referring to the laugher and teasing of peers, Raymond shows unusual understanding and acceptance. Another implicit message is that, in spite of his disability, Raymond can perform just like other kids. We see Raymond food shopping on his own, getting on base and scoring a run in baseball, and graduating from high school with his classmates.

As an educator, I question the educational value of this video for college classrooms. On

one hand, Raymond Hu is clearly a positive image of a person with Down syndrome, one who shows social, emotional, and artistic achievements. Teachers would benefit from seeing what is possible. However, this story perpetuates the erroneous notion that, with the right attitude and proper determination, one can conquer any condition.

This production shows that, despite his parents' fears, Raymond Hu is a dragon, a son of whom they can be proud. His accomplishments are heart-warming; however, I was left thinking about all those non-exceptional children whose stories will never be told.